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ABSTRACT

This publication is designed to help persons caring for elderly relatives maintain their own personal well-being while providing good care for their relative. Typical caregivers and caregiving activities are profiled. Two checklists are presented that are designed to help caregivers determine whether they are manifesting the warning signs of stress and identify the causes of their stress. Discussed in a section on stress management are the following basic strategies: set realistic goals and expectations (plan achievable goals and develop realistic expectations); establish limits; ask for and accept help; take care of oneself (express one's feelings, maintain one's health, and take time for oneself); and involve other people (hold a family conference, seek professional assistance, and use community resources). The following topics are covered in a section on caregiving at a distance: establishing a network, thinking before moving the family member requiring care, supporting the local caregiver, and being prepared for dramatic changes. Examined next are the pros and cons of placement in a care facility. A conclusion and list of related publications are provided.
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HOW TO MANAGE STRESS WHEN CARING FOR ELDERLY RELATIVES

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CONTENTS

Who Are You . . . the Caregiver	4
What is Caregiving?	4
Caregiving Stress: Symptoms and Causes	5
Strategies for Managing Stress	6
Caregiving at a Distance	14
Placement in a Care Facility	15
Conclusion	16
Additional References	16

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COPING WITH CAREGIVING

How to Manage Stress When Caring for Elderly Relatives

Family members who play a major role in caring for elderly relatives frequently ignore their own needs. Some find themselves virtually homebound and consumed by caregiving tasks. When caregiving is prolonged over months and years, the self-sacrifice is particularly harmful.

We have prepared this publication to help you maintain your personal well-being while providing quality care for an elderly relative. We will discuss the sources of stress and how you can master stress for your own benefit and that of the person for whom you are providing care. Remember, it's just as important to take care of your own needs as to provide the best care for your dependent loved one. As a caregiver, ignoring your own needs is not only potentially detrimental to you, but can also be harmful to the person who depends on you. Many nursing home placements are precipitated by the caregiver's exhaustion, illness, or death. This publication will help prevent such a situation for you and your family.

WHO ARE YOU . . . THE CAREGIVER

You may be a spouse, son, daughter, neighbor, close friend, or distant relative. You may be young or older yourself. No matter your relationship or age, as a caregiver you are making concessions and a personal sacrifice to provide care for another person. This can create areas of conflict and high levels of stress in your life.

If you're young, you probably have competing responsibilities for children, spouse, and job. If you're older, you may be adjusting to age-related changes including retirement, reduced income, widowhood, declining health, or different living arrangements. At any age, you probably have important goals and plans that are interrupted or postponed because of caregiving responsibilities.

As a caregiver you may be providing care out of love or out of a sense of obligation. More often than not, you feel both love and obligation. You may be providing the support alone or coordinating the work of others. You may find caregiving tasks satisfying and rewarding, or completely frustrating. This publication will help you understand your responses and will show you ways to reduce the conflict and stress caused by the demands of caregiving.

WHAT IS CAREGIVING?

Caregiving can evolve slowly, over a long period of time, or suddenly, in the case of illness or accident. Caregiving can mean having the older person live with you, near you, or hundreds of miles away. The elderly relative may be physically disabled or mentally incapacitated, or both. Depending on the specific need, caregiving can be a lot of different activities, including

- providing round-the-clock supervision
- supervising others who provide direct care

- shopping
- telephoning
- traveling to and from your relative's home

- maintaining two homes—yours and that of your relative
- lifting, bathing, dressing, and feeding
- managing incontinence
- managing financial and legal affairs
- providing social activity
- supervising medication
- arranging for health care
- listening, talking, and providing emotional support

Whether you are providing round-the-clock direct care or coordinating others who provide direct care, you are still the caregiver. You are responsible to some degree for another person's well-being. You may feel a sense of accomplishment in helping your dependent relative and may experience a new closeness in your relationship. Often a parent and child reach a higher level of acceptance and understanding when the child provides care for the mother or father. However, no matter how loving the relationship, caregiving almost always involves some personal sacrifice and stress which can be seen in

- emotional or physical exhaustion
- depression
- marital problems
- family problems
- alcohol or drug misuse
- conflict among life roles—spouse, employee, parent, and caregiver
- neglect or abuse of the older person

You may feel that there are too many expectations and not enough time and energy to meet them all. Unresolved, excessive, or prolonged stress results in what is often called "burnout". When challenges and demands are too great they drain our physical energy, time, health, and money. Becoming aware of how stress takes hold is the first step toward coping with it.

CAREGIVING STRESS— SYMPTOMS AND CAUSES

The Warning Signs of Stress

When you experience an unusual level of stress, certain warning signals occur. Answering the following questions will increase your awareness of these signs:

Yes No

- | | | |
|--------------------------|--------------------------|--|
| ☐ | ☐ | 1. Do you feel a loss of energy or zest for life? |
| ☐ | ☐ | 2. Do you feel out of control, exhibiting uncharacteristic emotions or actions? |
| ☐ | ☐ | 3. Do you lack interest in people or things that were formerly pleasurable? |
| ☐ | ☐ | 4. Are you becoming increasingly isolated? |
| ☐ | ☐ | 5. Are you consuming an increased amount of sleeping pills, medications, alcohol, caffeine, or cigarettes? |
| ☐ | ☐ | 6. Are you having increased health problems: for example, high blood pressure, ulcers, or difficulties with digestion? |
| ☐ | ☐ | 7. Do you have difficulty falling asleep at night, awakening early, or sleeping excessively? |
| ☐ | ☐ | 8. Are you experiencing appetite changes? |
| ☐ | ☐ | 9. Do you have problems with concentration or memory? |
| ☐ | ☐ | 10. Are you increasingly irritable or impatient with others? |
| ☐ | ☐ | 11. Do you have thoughts of suicide? |

A "yes" answer to even some of these questions can indicate stress that has become debilitating. Recognizing the source of this stress is the next step in dealing with its destructive effects.

The Causes of Stress

The causes of stress vary with the responsibilities and the caregiver. What creates stress for you may not create stress for someone else. There are, however,

some common sources of caregiving stress, which we raise in this next series of questions.

Yes No

- | | | |
|--------------------------|--------------------------|--|
| ☐ | ☐ | 1. Are you experiencing multiple demands on your time, energy, or money? What are they? |
| ☐ | ☐ | 2. Do you feel that your responsibilities conflict? Which ones? |
| ☐ | ☐ | 3. Is there a difference in expectations between your family, your boss, your dependent relative, yourself? What are they? |
| ☐ | ☐ | 4. Do you feel a lack of understanding about the older person's mental or physical condition? |
| ☐ | ☐ | 5. Do you have difficulty meeting your relative's physical or emotional needs? |
| ☐ | ☐ | 6. Are you pressured by financial decisions and lack of resources? |
| ☐ | ☐ | 7. Do you feel a loss of freedom ...a sense of being "trapped"? |
| ☐ | ☐ | 8. Is there disagreement among family members? |
| ☐ | ☐ | 9. Do you feel that other family members aren't doing their share? |
| ☐ | ☐ | 10. Does the older person place unrealistic demands and expectations on you? |
| ☐ | ☐ | 11. Is there a lack of open communication? |
| ☐ | ☐ | 12. Do other family members have negative attitudes that you have trouble contending with? |
| ☐ | ☐ | 13. Is there an observable deterioration in your family member that is painful to watch? |
| ☐ | ☐ | 14. Are there other problems with children, marriage, employment, or health? What are they? |

Now look carefully at the questions to which you answered "yes." You will want to focus your full attention on these specific sources of stress as we talk about ways to reduce stress.

STRATEGIES FOR MANAGING STRESS

Once you know the sources of stress, you must determine which ones you can do something about and which are beyond your control. Successful coping involves accepting what you can and cannot change.

For example, you will not be able to change a parent who has always been demanding and inflexible, but you can control how you respond to your parent's demands. If your father has a progressively debilitating illness, you can't change that. However, you can develop skills for coping with the changes brought on by his illness.

Usually some action can be taken to decrease stress. Changes do not need to be major to make an important difference. Sometimes letting go of unrealistic expectations, or adjusting your standards of how frequently or how well you perform a task (such as housekeeping) will make a big difference.

In general, professionals who have extensive experience working with caregivers agree on five basic strategies to help control the destructive effects of stress. They are:

- 1. Set realistic goals and expectations**
 - a. Plan achievable goals
 - b. Develop realistic expectations
- 2. Establish your limits**
- 3. Ask for and accept help**
- 4. Take care of yourself**
 - a. Express your feelings
 - b. Maintain your health
 - c. Take time for yourself
- 5. Involve other people**
 - a. Hold a family conference
 - b. Seek professional assistance
 - c. Use your community resources

Set Realistic Goals and Expectations

Plan achievable goals

What do you want to accomplish? The basic goals of caregiving are to assure the care receiver's quality of life, physical comfort, and safety. These goals can be accomplished in many ways. For example, you may be the direct care provider or you may be a "care manager" who arranges, coordinates, and monitors the services your family member requires.

In setting goals it's important to consider how caregiving is likely to affect other areas of your life. How is your health? What is your relationship with your spouse and children? What other demands and obligations do you have? Are you employed? Preventing caregiver burnout means accepting the limitations of what you can accomplish.

In addition to understanding yourself, you also need to know how the illness or disability affects your family member. Objectivity about your situation is important . . . but not always easy. You need to know what is likely to occur medically and behaviorally now and in the future. For example, sometimes a mentally impaired person's behavior or moods can be baffling. It can appear that he or she is intentionally being difficult, acting helpless, or refusing to communicate. If this behavior occurs, consult with a professional who is knowledgeable about your family member's condition. A professional can often assess whether behavior is intentional or disease-related and therefore unintentional. By determining the reason for behavior, you can adjust your expectations and responses.

You will see results more often if you select goals that are specific and achievable. Specific goals are short-term and focused on a clear problem. If you have only broad long-range goals, you are more likely to experience frustration. You may have a long-range goal of getting your father back to his own home, if possible. However, some specific, achievable, short-term goals might include:

- Keeping your father's spirits up by arranging for friends and family to visit.

- Developing your father's physical strength by arranging for people to take him on daily walks.

The degree to which short-term goals are accomplished will help you to assess the practicality of long-term goals. Professionals involved in the care of your family member can help set realistic short-term goals.

Goals also need to be considered in terms of the ill person's personality and capabilities. Some caregivers are driven by goals such as "make mother happy." Given mother's personality or the accumulation of recent losses, this may be completely unachievable. Such an objective creates a heavy burden and you'll probably feel that you'll never attain it. A specific and achievable accomplishment, however, might be to provide a pleasurable activity at least once a week for your mother, perhaps spending 2 hours each week doing something enjoyable like visiting friends or working a puzzle. If you set such specific goals, you are more likely to feel satisfied with your progress.

Develop realistic expectations

How realistic are your expectations? Do you often feel that if only you could do more, things would be better for your family member—your mother would be happier, your father less confused, your spouse less depressed? Do you sometimes think, "Mother took care of me when I was a child. I should be able to care for her as well as she took care of me?"

Caregivers frequently struggle to balance their self-expectations with what they can actually achieve. Sometimes we expect too much of ourselves and we get into a state of constant worry or anxiety because we think we are not doing what we should. Women caregivers are particularly vulnerable to "shoulds." Because of the way females are raised in our society, women caregivers often believe they should be able to do everything themselves. When unable to do so, they feel guilty or depressed.

Sometimes old promises drive us to do more than what is realistic. Promises can get in the way of objectively assessing the current situation. They reduce our objectivity and ability to make the best decisions for everyone concerned. It's important not to let old promises, "shoulds," or guilt guide caregiving decisions.

If an old promise, such as "Mom, I'll never put you in a nursing home," is creating difficulties for you, compare the current situation to the situation when the promise was made. You'll probably find the situation has changed considerably. If it hasn't changed, it might indeed be possible to fulfill the promise. However, the promise made under one condition may not be viable under the current situation because of changes in your family member's health or in your life circumstances.

Establish Your Limits

You have a right to set limits on what you will do! It's all right to say "no." Taking these steps, however, can be difficult, especially if you must make painful choices. There are times, of course, when it's necessary to go beyond limits. When additional resources simply are not available, you may not have a choice. In general, however, providing care at the expense of your mental and physical health or relationships with other family members does not benefit anyone!

When you set limits, it's important to communicate them to your family and to your ill relative. This may be particularly painful to do with a parent or spouse. But remember, to not do so will only increase your stress.

Discussing limits in caregiving is usually easier if you consider other ways in which your relative's needs can be met. Share information about those options at the same time you talk about your limits.

Ask For and Accept Help

How do you respond to offers of help? Is it difficult to ask for assistance? When you do request support, are you specific enough so people know exactly what you

want? Do you expect close family members to know when you need help? Do you refuse offers of help, but feel exhausted or resent not receiving assistance? Do you feel "I should be able to do it alone?"

Resistance to accepting help is a common cause of stress and depression among caregivers. In our culture, with its emphasis on "independence" and "doing it alone," it's not easy to request help. Some caregivers view asking for help as a sign of helplessness, inadequacy, or failure. Actually, asking for needed help is just the opposite. Knowing your limits and reaching out for assistance before you are beyond your limits is an important characteristic of a strong individual. It also helps ensure quality care for your family member.

Being a martyr benefits no one. Refusing help will not make you a better caregiver—it will make you exhausted and probably irritable.

Family members, neighbors, and friends are often willing to help. But sometimes people hesitate to ask if they can help because they are frightened by illness, feel uncomfortable around the ill person, don't want to interfere, or don't know what they can do. You may have refused earlier offers of assistance, or you may appear to have everything under control.

People can best help if you tell them exactly what your needs are and how they can help. Be specific and positive. When family or friends ask how they can help, make a specific suggestion. For example, say, "Could you visit with mother for an hour so I can go to the store?" or "When you go to the store could you pick up a few things I need?" Tasks unrelated to caregiving may be easier for some people. If you can be flexible, ask when would be the best time for them. It's also important to show appreciation for any help received. Let people know how much their support means to you.

People are always less likely to respond to requests that are demanding, manipulative, or guilt-provoking. One of the least productive attitudes a caregiver can have is to expect others "to know" when help is

needed. People are not mind readers. Keep in mind, too, that others may have obligations or problems of which you are not aware, but which limit the assistance they can provide.

Take Care of Yourself

Express your feelings

It's very important that you find someone with whom you can talk openly about your situation and your emotions.

Understand your emotions. Being a caregiver and seeing the decline of a loved one is not easy. Almost every caregiver experiences a wide range of emotions, some of which are conflicting, confusing, and ambivalent. You may feel love, sadness, frustration, dislike, repugnancy, guilt, grief, fear, resentment, hopelessness, or despair. You may feel angry about the increased dependency of your family member and the multiple demands on your time, energy, and money. As changes occur in your family member, you may grieve for the loss of your relative as he or she used to be. Feeling unappreciated is sometimes a problem for the caregiver, particularly if the ill person expresses only dissatisfaction or is unable to show appreciation.

These feelings are normal. They are neither "good" nor "bad," nor do they reflect the degree of your caring. Feeling angry does not mean you love your relative less. What is important is how you handle your feelings. Learning to express feelings and to deal with tensions in constructive ways is vital to your emotional and physical health.

Stress has fewer negative effects for people who admit their feelings and accept them. When you acknowledge and understand your emotions you can then control them. Repressing or denying feelings decreases energy, and can cause irritability, depression, or physical problems. Your feelings can also greatly influence your judgment.

Some feelings are very hard to share directly. If this is true for you, find an indirect way to do so—write them down, get involved in vigorous physical activity, chop wood, punch a pillow.

Use assertive communication. Feelings should not be expressed in a manipulative or hostile way, to get even with someone, or to create a sense of guilt. Such responses are not constructive and may indicate you are stuck in an "anger trap." To avoid the "anger trap," use assertive communication. When conflicts arise, talk about them with those involved. Express yourself in terms of your own feelings. Use "I" statements and describe specifically whatever is bothering you. For example, "I was upset when you didn't make the doctor's appointment for Mom that you said you would."

Avoid "you" or blaming statements that imply others are responsible for your feelings. Blaming statements, such as "you don't care about Mom," "you make me so angry," "you never follow through on anything," or "you always let me down" sound accusatory and tend to create defensive arguments. Saying "I feel, I need, I expect, I choose, I believe," is more effective and less threatening. Avoid using terms like "always" and "never"—the person will usually deny these statements because "never" and "always" are rarely true. Assertive communication encourages problem-solving.

Recognition and appreciation are important needs. If you do not feel appreciated, you need to let others know. Ask for positive feedback. If the care receiver is able to communicate, tell him or her your feelings.

Join a support group. Most people benefit from sharing their feelings with someone who is supportive and listens nonjudgmentally. Such sharing with a confidant often relieves tension, helps give a new perspective of the situation, increases mutual understanding, and builds support.

In some areas, support groups have developed for this kind of sharing. Some groups are oriented to specific diseases like cancer, Parkinson's disease, lung disease, or Alzheimer's disease and related dementias. Others are for family caregivers in general. Many caregivers find that support groups help them feel less alone. Support groups give an opportunity to share openly with

others who understand and to learn techniques for coping. They also provide an opportunity to share your knowledge and to help other group members. Information about local support groups may be obtained by contacting a local hospital or home health agency, the Area Agency on Aging, or disease-related associations such as the Cancer Society or the Alzheimer's Disease and Related Disorders Association.

Maintain your health

To provide effective care, it's vital that you maintain your own health. Neglecting your health has long-range consequences, not only for you, but for the person who needs your care. Proper diet, sleep, exercise, and attention to your health problems are essential.

Without adequate nutrition and rest, you will feel exhausted, discouraged, and depressed. If interrupted sleep is a major problem, find someone who will provide occasional or even regular night duty.

Exercise has many benefits—it promotes better sleep, reduces tension and depression, lifts spirits, and increases energy. If you feel that exercising would be just one more demand, think of ways to incorporate it into your daily routine. If your family member is physically able, perhaps you could walk together. While talking on the telephone or watching television, do stretching exercises. Relaxation techniques are another way to reduce stress. Find an activity you enjoy, so exercise becomes a pleasurable event for you. Do it 20 to 30 minutes three times a week.

Humor is a powerful antidote to stress. Laughing quickens the pulse rate, stimulates the blood circulation, activates muscles, increases oxygen intake, and fosters physical relaxation. If you have forgotten how to laugh, try to be around people who still know how—it's contagious.

Take time for yourself

Do you value yourself and your personal needs? What do you do for personal renewal? Do you save some time for yourself out of each day and take

occasional extended breaks? Or are you so involved with caregiving tasks that you have little or no time for yourself?

All too often, caregivers place their own needs last. Helping an elderly relative should not mean giving up all activities and relationships with other people. Studies show that sacrificing oneself in the care of another and removing pleasurable events from one's life can lead to emotional exhaustion, depression, and physical illness in caregivers. Taking breaks from caregiving is essential for both full-time and part-time caregivers. You have a right—and even a responsibility—to take time away from caregiving.

Refusing to take breaks for self-renewal can be detrimental to the care receiver as well as to yourself. It can increase the dependency of the care receiver. The ill person who sees few people regularly may benefit from being with others while you take a break. Sometimes, too, the care receiver will be more responsive with another person. For example, he or she may participate more actively in rehabilitation exercises in your absence.

Objective evaluation usually shows that others can provide adequate care, at least for a short time. If you hesitate to leave because you are concerned about what might happen while you are away, ask yourself, "What is the worst possible thing that could happen?" Then make contingency plans for handling "the worst."

Consider getting breaks early in caregiving. If you wait until you are "burned out," these breaks will not be enough. It's important to make a plan for regular breaks, decide on the time, date, and activity—then follow through!

Finding appropriate substitute care takes time and preparation. In some areas, community respite care has been developed to provide in-home or out-of-home support. Respite services may be available for a few hours, a day, overnight, weekends, a week or longer, and on a planned or emergency basis. Respite providers may be trained volunteers or paid staff.

In-home respite care can include companion-type or supervision services or the temporary use of homemaker and/or home health services. It has the advantage of keeping the person in familiar surroundings. Out-of-home care includes adult day care or short stays in adult foster care homes, nursing homes, or hospitals.

Regardless of the respite care services you select, you will want to prepare for the service by answering these important questions:

- What type of help do I really need (regular or occasional)?
- What times would be best for me?
- How much advance notice do I need to give the substitute care provider?
- What information should the respite provider have about the elder's special needs and routine?
- How should the respite provider deal with an emergency (who and where is the back-up)?
- How can I prepare the older person for my leaving?

If you've always been available, you may need to prepare your family member for your leaving. You might try a "trial period." Have the substitute care provider visit a few times while you are present or take only a brief break in the beginning to see how the arrangement will work. If your relative protests your leaving, you will want to acknowledge his or her feelings, but state your need for a break. For example, you might say, "Dad, I know it's hard to have me leave, but I am exhausted and I need to get away for awhile." For the memory-impaired person, it may help to leave a note indicating the time you will return.

Involve Other People

Hold a family conference

Although care for an older person may be provided primarily by one person, all family members should be involved in the

planning and continual support. One strategy for deciding how to share caregiving responsibilities is the family conference.

A family conference should be held as early as possible after the need for caregiving arises. The conference gives everyone an opportunity to discuss caregiving concerns, identify potential problems and solutions, and negotiate the sharing of caregiving tasks. The conference can also clarify each person's expectations and minimize misunderstandings.

Include everyone. Everyone who is concerned and may be affected by care decisions should be involved in the family conference. Siblings, spouse, other relatives, housemates, neighbors, close friends, and the person for whom plans are being made should be involved. If illness prevents the care receiver from being involved directly, you should get his or her input and keep him or her informed. Remember, having as much control as possible over our lives is important to all of us, regardless of our age or illness.

A family member should not be excluded from a family conference because of distance, personality, family history with the older person, or limited resources. It's just as important to include a difficult, argumentative family member, or one who never visits, as it is to involve those who are supportive.

Telephoning distant relatives to get their input and to keep them informed will help them feel a part of the decision-making. Involvement of all family members in developing a caregiving plan ensures greater success and support for the plan, and helps prevent later undermining of decisions.

Consider a two-step conference. Sometimes families find it helpful to hold a two-step conference. The first meeting is held without the older person for the purpose of airing ideas and feelings, identifying concerns, looking at gaps in information, and discussing responsibilities for each family member. The purpose should not be to make the decision or to "gang up" on the older person. A second

meeting is then held with the older person, who is actively involved in looking at the options and making decisions.

Plan for success. A family conference is most successful when you give attention to these considerations:

- Before the conference, ask family members to list their concerns and tasks they are willing to do.
- Hold the conference in a neutral place. Holding the conference in the older person's home will help give him or her a greater sense of control.
- Create a feeling of support and confidentiality.
- Keep the conference focused on the current concern rather than on other issues or past conflicts.
- Be certain everyone has the opportunity to express feelings, voice preferences, and offer suggestions without being "put down."
- Focus on the positive. Identify what each person can do, but encourage everyone to be honest about their limitations. Sharing information about other responsibilities can help others understand why the support must be limited.
- Prepare a written plan listing what each person will do and when they will do it. Keep it flexible. A written plan can prevent later disagreements about who agreed to what, and can better assure that needed tasks will be completed.

Realize there may be conflict. A family conference is not always easy, and in some families, it is impossible. It's most difficult for families who have never discussed feelings and family concerns. Where conflicts already exist among family members, decision-making is difficult. When family members come together after years of separation, old conflicts can re-emerge with regard to relationships, family roles, expectations, and even inheritance.

Family members often have different perceptions about the care needs of an older person, the best care option, the division of care tasks, and how money should be spent. For example, one brother might not want a parent's resources—his potential inheritance—spent for in-home services. He may prefer that the family provide the needed care, while another brother feels "Mom's money is there to spend on her" and prefers to purchase care services.

Beliefs about "what is best" often differ, creating conflict. One person may feel that the impaired person should be kept at home, regardless of what needs to be done; another may feel that a different living arrangement is needed for the person's health and safety. Intense conflicts often result when one person insists that the older person be maintained at home and another is fighting for nursing home placement. Bringing in an objective third party skilled in working with the elderly and their families can often help.

If family conflicts or hidden resentments prevent rational discussion, seek professional guidance. A counselor, health or social service professional, or member of the clergy trained in family counseling can help you deal with family conflicts. He or she also may be able to guide the family conference.

Obtain professional guidance

Receiving professional advice and assistance can help reduce some of the causes of stress. You should consider seeking professional guidance under the following circumstances:

- You find yourself using alcohol or drugs to forget your problems, relieve stress, fall asleep at night, or get yourself going in the morning. Substance abuse can impair your judgment and contribute to your feelings of inadequacy and guilt. It can also result in neglectful or abusive behavior.
- You become depressed. Untreated depression can negatively affect your health and your responses to the ill person.

- You don't understand your family member's behavior or don't know how to deal with specific care tasks.

- You find yourself feeling resentment or losing emotional control, or neglecting, humiliating, or becoming physically rough with a family member. These behaviors are often caused by exhaustion, stress, or lack of resources.

- You are being physically or emotionally abused by your impaired family member.

- Your family cannot resolve problems or reach agreement on care decisions.

- You feel a conflict between caregiving and other responsibilities.

A professional can often help you gain objectivity and a clearer perspective of the situation. Don't be afraid to seek help and don't wait until you are overwhelmed by a crisis. Getting help is a sign of personal strength, not weakness, and will enable you to be a more effective caregiver.

You can obtain the names of individuals skilled in working with older adults and their families through senior centers; hospitals; health, family, and social service agencies. When you call a professional, state your specific need and ask the person about his or her training and experience with your problem. If the person is unable to assist you, ask for names of others who can help.

Use your community resources

In recent years, a range of community services has developed to help older persons and their families. Specific programs designed for caregivers include respite care programs and support groups, as previously discussed. In addition, programs designed to directly serve the elderly can help the caregiver. Paying for outside assistance early in the caregiving process is generally less expensive than if you wait until you become overwhelmed and exhausted. At that point, your options are likely to be fewer and more expensive, and you may be paying health bills for yourself as well as for your relative.

Available services vary between communities, but some of the most common include:

Companions or friendly visitors provide companionship, friendship, support, or supervision to older adults for a few hours. In some areas, paid companions are available to stay through the evening and night. For older persons living alone, friendly visitors can provide a safety check as well as companionship. In general, they do not provide housekeeping or personal care services.

Telephone reassurance provides regular telephone calls to home-bound ill or disabled persons.

In-home medical alert program ("Life-line")—the impaired person wears an electronic device that sends a signal to a central dispatcher, often located at a hospital, if he or she falls or needs help. Emergency assistance is summoned if the older person does not answer the telephone.

Chore services provide help with yardwork, minor home repair, and winterization. In some areas, chore services also include assistance with household chores, grocery shopping, laundry, meal preparation, and cleaning.

Homemaker services assist with light housecleaning, shopping, laundry, and food preparation.

Home health aides provide help with personal care activities, such as bathing, feeding, walking, and toileting. Aides provided by a certified home health agency are trained and supervised by a registered nurse.

Home-delivered meals are nutritious meals delivered to home-bound elders, usually around the lunch hour. The days for home-delivery of meals vary from one area to another.

Congregate meals provide inexpensive, nutritious meals in a group setting in senior centers or other community settings. Transportation is often available for those unable to drive. Frequently the mealtime includes recreational and social activities.

Transportation services provide vans or buses that can be called to transport to and from doctors' appointments, rehabilitation sessions, congregate meal programs, and sometimes grocery shopping and other activities. Transportation services must be scheduled in advance.

Adult day care—a special program for people who are either physically or mentally incapable of independent living and need protective services during the day. Programs vary, but often offer health and medical monitoring, meals, and recreational group activities. The program enables some caregivers to continue their employment and care for their relative at the same time.

Day treatment provides assistance to individuals who are mentally ill or have a mood or thought disorder that significantly impairs judgment or behavior. Psychosocial rehabilitation is provided to assist these people in their daily life.

Home health nurses offer health assessment and home health care to persons who need nursing care at home. If needed, other services such as physical therapy, speech therapy, and home health aide services are provided.

Some of these programs require a fee, which may be calculated on a sliding scale that is determined by ability to pay. Other services may be free or have a voluntary donation because they are provided by volunteers, government, or charitable organizations. Some programs also have age, income, or other eligibility requirements. When calling an agency, state your needs as clearly as possible and remember to ask about eligibility requirements and costs. Contacting agencies requires considerable time and energy. If you feel you don't have time to make the necessary calls, enlist the help of other family members and friends. They can help make the contacts or provide care for your family member while you call.

Your local Area Agency on Aging is a good place to find out about programs and services in your community. It may also be called Senior Service Division, Aging

Services, or the Office on Aging. Use the telephone prompter on the back page to help you get the best information from agencies.

If an agency representative cannot answer your questions, ask to speak to the supervisor. Avoid becoming irritated or angry. Say something like, "I appreciate your assistance, but I'd like to ask your supervisor some additional questions." If the supervisor is not available, you should ask for the best time to call back. Before you hang up, ask if there is a direct telephone number for the supervisor.

Whether or not you presently need assistance, explore community services for future needs. Find out about services offered by public and private sectors, and record the information for future use. You never know when you may need a service, and in a hurry.

CAREGIVING AT A DISTANCE

Distance can make caregiving more complicated. You may get calls from neighbors and friends who are concerned about your relative's health or living situation, but it's difficult to know how well your older relative is functioning without being near.

Establish a Network

You may be driving or flying back and forth to repeated crises or spending long weekends and vacations "getting things in order" for your family member. If this is true for you, you will need to establish a network of neighbors, friends, and professionals in your relative's community who can help assess your relative's needs and arrange for services. In some communities, health care professionals in public agencies and private businesses offer the service of coordinating the care of older persons whose primary relatives live at a distance.

Think Before You Move Your Family Member

If you are an only child or have primary responsibility for your family member, or if there are no relatives living nearby, you

may face the tough decision of whether to move your relative closer to you. If you are considering moving a parent to your community or into your home, carefully weigh the advantages and disadvantages for your relative, yourself, and your family. Since needs change over time, weigh the decision for the future as well as for the present.

A move can separate your family member from long-established roots that are not easily replaced. This can present a major problem. The person may become entirely dependent on you for social and emotional support. This is more difficult if your family member does not make friends easily or is limited in mobility or verbal skills.

A move should also be considered in light of your past relationship with the family member. Can you tolerate increased and intensified contact with your relative? Relationships that have been difficult in the past or succeeded because of geographic distance often require extensive adjustment when the distance is removed. **Remember, arranging for needed services for a family member is sometimes the most appropriate means of caregiving.**

Support the Local Caregiver

If you live at a distance, it's critical to support, in whatever way you can, the caregiver who has day-to-day responsibility. Maintain regular contact. Call frequently rather than expecting the caregiver to call you. Ask, "What can I do to help?" Make a list of tasks you are willing and able to do and share this list with the caregiver. Perhaps you can give the caregiver a break by spending a week with your older family member, paying for a housekeeper or respite care provider once a week, or inviting your older family member to visit you. Calling your older relative weekly, making frozen meals, or managing the person's finances may provide needed relief for the primary caregiver.

Persons who provide daily support to an older family member frequently feel they are not appreciated. The person receiving care sometimes takes out his or her feelings of loss on those providing the day-to-day support and talks in glowing

terms about sons and daughters who live at a distance. If this happens, do not allow the older person to put down the primary caregiver in your presence. It will help if you also let the primary caregiver know you understand the situation and appreciate what he or she does on a day-to-day basis.

Conflict can arise between family members who live near the older person and those who live at a distance, because of their different perspectives. If you spend only a few days with your relative, the care needs may not seem as great as if you have daily responsibility. Sometimes, too, the older person will "perk up" in response to a visit by a rarely seen family member and will fail to display the symptoms and difficult behavior that occurred before the visit. At times, someone will "dump" on one person and show a cheerful side to another. This behavior can be related to distance or to past relationships.

Don't let apparent differences in behavior between what you see and what the caregiver has told you discredit the caregiver. To accurately assess your relative's functioning you may need an extended visit and to talk with professionals involved in your relative's care.

Remember, too, that local caregivers often have to compromise with the older person and accept imperfect solutions to problems. For example, if you find your father's home is not as well kept as you feel it should be, it may not be that family members are neglectful. Your father may be refusing help with the household chores.

Be Prepared for Dramatic Changes

If you live at a distance and are unable to visit regularly, you may be shocked at the deterioration in your relative when you do visit. You may become upset because you have not been told "just how bad Mom or Dad is." When changes occur gradually, family members who have daily contact are often not aware of the degree of change because they have gradually adjusted to them. When you live at a distance, you have only two points of reference—the last time and now. The changes can appear dramatic.

You can help by keeping your shock from placing an additional burden on the caregiver. Unloading on the primary caregiver may create just one more stress. The caregiver may begin resenting your visits or struggle to make the ill person appear better than he or she really is.

If you are a local family member, try to understand the different perspective of out-of-town relatives. Keep them informed and involved in decisions. Let them know what the needs are and request specific help, rather than resenting them for "not doing more". And, remember, show appreciation for any help you receive.

PLACEMENT IN A CARE FACILITY

There may come a time when you or other family members cannot provide direct care or in-home services are no longer appropriate to meet your older relative's care needs. Placement of the frail older person in adult foster care or a care facility is sometimes the best decision for everyone. However, it may be one of the most difficult decisions you will ever make.

A move of your family member to a care facility does not mean your caring relationship ends. It merely changes the relationship, and often for the better. It signifies an extension, rather than a termination, of your caring. You become a valuable member of the health care team by participating in planning care, assisting staff to understand your family member's needs, and monitoring the care he or she receives.

The potential benefits of placement for your relative include increased social contact, recreational and social activities, and rehabilitation services. Also, when you are no longer devoting your time to meeting the physical and safety needs of your family member, you will be better able to meet some of his or her emotional and social needs. Meeting these needs is very important. Almost any trained person can assist your relative with the activities of daily living—dressing, bathing, and feeding. Family and friends, however, are in the best position to share special memories and give your relative a feeling of belonging and of being loved. These feelings add immeasurably to someone's quality of life.

CONCLUSION

Caregiving decisions should not be based only on the needs and desires of the older person. You must also consider the consequences of caregiving decisions for yourself and other family members. Making these decisions is an essential part of self-care, which in turn will help you provide effective care for others.

Even though you follow the suggestions we have provided here, not everything will be as you would like. There will be times when you wish you had done things differently. You are only human. If you make a mistake, admit it and learn from it, and then go on. There is no advantage in being plagued by feelings of guilt.

Too often caregivers focus on what they have not done well. Remind yourself of the many things you have done well...it will make you feel better about yourself. Ask yourself: What are my personal strengths? How have I made a difference for my family member? What things have I done that I feel good about? You are doing many things right. Don't fail to give yourself the credit you're due.

ADDITIONAL REFERENCES

These publications are available from Agricultural Communications, Publications Orders, Oregon State University, Corvallis, OR 97333-2119. Please add 25¢ shipping and handling for orders up to \$2.50. For orders between \$2.50 and \$100, add 15 percent shipping and handling. For orders of \$100 or more, please call (503) 754-2513 for a price quote.

Aging Parents: Helping When Health Fails by V. L. Schmall and L. Isbell. Pacific Northwest Extension publication PNW 246, Corvallis, Oregon State University, 1984. Single copy 50¢.

Families and Aging: A Guide to Legal Concerns by V. L. Schmall, J. McGinnis, V. Salvi, and G. C. Steinke. Oregon State University Extension Service Circular 1221, Corvallis, 1985. Single copy \$1.25.

Growing Older: Sensory Changes by V. L. Schmall. Pacific Northwest Extension publication PNW 196, Corvallis, Oregon State University, 1980. Single copy 25¢.

Helping Memory-Impaired Elders: A Guide for Caregivers by V. L. Schmall. Pacific Northwest Extension publication PNW 314, Corvallis, Oregon State University, in press. Single copy 50¢.

When Death Comes: Funerals & Alternative Arrangements by V. L. Schmall and C. Pratt. Oregon State University Extension Circular 1243, Corvallis, Oregon, 1986. Single copy \$1.00.

TELEPHONE PROMPTER

Place this prompter by your telephone when you call about community services. It will remind you of the questions you should ask.

My name is _____

I'm caring for _____

I need _____

Can you help me?

If no:

Can you give me another name to call?

If yes:

What services do you provide?

What are the costs? How are they paid?

What are the eligibility requirements?

How long must we wait?

Can you send a brochure or application?

To whom am I speaking?

Do I need to speak to anybody else?